Patient reported outcome in neuromuscular diseases: The QoL-NMD. Qualitative and quantitative generation of items


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Introduction.– Screening for anxiety and depression is likely to be overestimated in patients with physical disabilities such as Steinert dystrophy patients. This overestimation results from the high weight of scores for items assessing motor adynmia and in the other hand, the characteristic anemic face these patients present. Hospital Anxiety Depression Scale (HADS) has the advantage of not inquiring items on motor skills. This work seeks to verify the reliability of the anxiety and depression HADS subscales and their reproducibilities in patients with Steinert myotonia.

Materials and methods.– Thirty-five patients suffering from Steinert myotonia (11 men, 24 women) responded twice to the HADS questionnaire. The delay between the two HADS evaluation was on average 18 ± 12 days. It was verified by examination that no health problem had occurred between test and retest of the questionnaire HADS. The HADS is a self-administered questionnaire comprising 14 items, 7 items measuring the depression likelihood, 7 other items assessing the anxiety risk. The reliability of two subscales was checked by calculating Cronbach alpha coefficients and test-retest reproducibility of the scores by intraclass correlation coefficients (ICC).

Results.– For the subscale ‘anxiety’ test and retest scores were respectively 7.94 ± 4 (1–19 min–max) and 6.42 ± 3.68 (1–14 min–max). The coefficient Cronbach’s alpha of the 7 items of the subscale ‘anxiety’ was satisfactory at 0.74. The ICC was good at 0.77. Six patients had a score ≥ 11/21 relating a pathological anxiety (17%).

For the subscale ‘depression’, test and retest scores were respectively 5.85 ± 3.75 (1–16 min–max) and 5.94 ± 4.25 (0–18 min–max). The Cronbach’s alpha was 0.82 and ICC 0.92. Four patients were therefore screened as ‘depressed’ (12%).

Conclusion.– The HADS is a self-administered questionnaire which measures reliability and reproducibility features of anxiety and depression in Steinert myotonia peoples.